



Family News

News and Information for Families of individuals served at Muscatatuck SDC and Madison State Hospital during the transition to community-based services.

MEETING ANNOUNCEMENT

The next meeting of the
**Southeast Regional Project
Team** will be:

March 27, 2002

10 a.m. - Noon

ISTA Building

Second Floor Conference Center
150 W. Market St., Indianapolis, IN
(across from the State House)

HANDY NUMBERS AND WEB SITES:

MSDC/MSH Info Hotline:

1-800-903-9822

www.IN.gov/fssa/transition

Maintained by FSSA to answer
your questions.

DD Waiver Ombudsman:

1-800-622-4484

Available to respond to your
comments and questions.

The Arc of Indiana:

1-800-382-9100

www.arcind.org

www.thearcink.org

A statewide group that advocates
on behalf of people with mental
retardation and related
disabilities and their families.

Area Agency on Aging:

1-800-986-3505

www.iaaa.org

AAAs provide case
management, transportation,
and other services to older adults
and people with disabilities. Call
to find the agency closest to you.

Southern Indiana Center for Independent Living (SICIL):

1-800-845-6914

Part of Indiana's Independent
Living Service system, SICIL
provides people with disabilities
with information and referral,
advocacy and other services.

Deinstitutionalization In America

*In this issue, David Mank, Ph.D.,
Director: Indiana Institute on Disability
and Community, and Professor, School
of Education; Indiana University,
reviews Deinstitutionalization efforts
across the U.S.*

**Why deinstitutionalize and
what happens when people
with significant disabilities
leave large congregate facilities?**

For more than 30 years, states
across the USA have been devel-
oping more person centered,
individualized and community
based lives for people with devel-
opmental disabilities and people
with mental illness. More than
20 detailed studies have been
conducted across the country,
including studies in Indiana (Cen-
tral State Hospital and New Castle
Developmental Center) about
what happens to people when
they leave large congregate set-
tings. All of these studies tell
the same story. People with dis-
abilities, including people with
severe and multiple disabilities,
show increases in independence,
fewer problem behaviors,
increases in choice making,
increases in relationships with
people without disabilities and
increases in employment and
earnings.

In addition, these studies show
increases in participation in com-
munity activities. Also, neighbors
develop positive attitudes about
their neighbors with disabilities.
And, over time, the costs are
about the same and often less
in the community than in large
settings.

**Are people at risk? Is it safe
in the community?**

It is important to note that a
move from a large setting to a small
community home does NOT mean
that people must become more
independent and more able to 'be
on their own.' Supervision and
supports follow people into the
community and in many situations
this support is full time, 24 hours a
day and includes medical care and
therapies. Living in the community
does not mean giving up support,
medical care, supervision nor other
things a person needs to be safe
and happy. By every measure, living
in the community shows clear
increases in quality of life compared
to living in larger, congregate set-
tings. And, the supports, supervision
and care 'goes with the person' to
their new home. And, people with
disabilities, and their families, choose
where to live, who to live with and
decide about the programs that

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Centers for Independent Living

A Brief History and Indiana Services

Centers for Independent Living (CIL) are organizations that help people with disabilities lead self-determined lives. CILs provide several core services - information and referral, advocacy, peer counseling, and independent living skills training - that help people with disabilities learn their options, make informed choices, and express their voices about matters affecting their lives.

The independent living movement began in Berkeley, California in the 1960s by Ed Roberts, a University of California student who used a ventilator and a wheelchair. Mr. Roberts was unhappy with the institutional living situation set up for him by the university and instead worked with university officials to set up a program that provided support services for students with disabilities. Mr. Roberts took the self-help concept he created on campus and moved it into the community by starting the first Center for Independent Living in Berkeley. Next, Mr. Roberts worked as a consultant to federal and state government eventually becoming the Director of Rehabilitation for the State of California.

Following Ed Roberts' lead, CILs began operating across the country. Indiana has its own independent living service system consisting of Centers from Ft. Wayne to Bedford and from Terre Haute to Richmond. For more information, please contact the Center closest to you.

Southern Indiana Center for Independent Living

Al Tolbert, Executive Director
3300 W. 16th St.
Bedford, IN 47421
Phone: 812-277-9626 (V/TTY)
Fax: 812- 277-9628
Toll free: 800-845-6914
E-mail: sicil@tima.com

League for the Blind and Disabled

David Nelson, Executive Director
5821 South Anthony Blvd.
Fort Wayne, IN 46816
Phone: 219-441-0551 (office, V/TTY)
Fax: 219-441-7760
Toll free: 800-889-3443
E-mail: lbdlfw@ctlnet.com

Indianapolis Resource Center for Independent Living

Emma Sullivan and Melissa Madill, Co-Executive Directors
2110 N. Capitol Avenue
Indianapolis, IN 46202
Phone: 317-596-6440 (office, V/TTY)
Fax: 317-596-6446
Toll free: 800-860-7181
E-mail: mjmadill@netdirect.net

Everybody Counts Center for Independent Living

Teresa Torres, Executive Director
9111 Broadway, Suite A
Broadfield Center
Merrillville, IN 46410
Phone: 219-769-5055 (office)
Fax: 219-769-5325
TTY: 219-756-3323
Toll free: 888-769-3636
E-mail: ecounts@netnitco.net

Future Choices, Inc.

Beth Quarles, Executive Director
309 N. High Street
Muncie, IN 47305
Phone: 765-741-8332
Fax: 765-741-8333
E-mail: FutureChoicesInc@aol.com

Independent Living Center of Eastern Indiana

Ed Bell, Executive Director
Workforce Development Center
3771 E. South "A" St.
Richmond, IN 47374
Phone: 765-939-9226
Fax: 765-966-3431
TTY: 765-966-8229
Toll free: 877-939-9226
E-mail: ilcein@ruraltek.com

Wabash Independent Living and Learning Center

Teresa Mager, Executive Director
7 "J" Meadows Center
Terre Haute, IN 47803
Phone: 812- 232-9455
Fax: 812-234-1536
Toll free: 877-915-9455
Info@thewillcenter.org

Assistive Technology Training and Information Center

Patricia Stewart, Executive Director
1721 Washington Avenue
Vincennes, IN 47591
Phone: 812-886-0575 (office, TTY)
Fax: 812-886-1128
Toll Free: 800-96ATTIC
Email: inattic1@aol.com

The Person Centered Planning Process

This article reviews the components of the person centered planning process. Each consumer and family goes through every step of this important process in preparation for transitioning to a new living arrangement.

The Lifestyle Plan

The purpose of a lifestyle plan is to learn how the individual wants to live and to develop a plan for helping the person move towards that life. The emphasis is on getting to know the person and what they really need and want as a person. Participants at this planning meeting include the individual and family, staff, and friends who know the individual's needs, interests, and desires.

The Support Plan

The support plan spells out exactly what supports are needed by each consumer. The plan should include the type of support needed and the frequency/intensity of the support. Participants in this meeting should include the individual and family, provider staff, and others who know the individual and are coordinating their services.

The Pre-Placement Visit

A quality monitor makes these visits prior to an individual having any site visits. The purpose of these visits is to evaluate the physical environment to assure that the environment is appropriate to an individual's needs.

Site Visits

Site visits may be helpful in determining if a place is a good match for a specific individual. Site visits allow a person to "test drive" a possible placement. These visits are recommended, but not required.

Discharge Plan Meeting

This meeting is a review of the proposed supports outlined in the support plan. The facility staff discusses current needs and recommendations for placement supports. Provider staff discusses how to address the proposed supports. This meeting is typically held at least one week prior to placement.

Exit Conference Meeting

This is the final chance to review the support plan that will be followed in the new place where someone is moving. It allows one more opportunity to add/delete from the support plan if site visits indicate a need to modify the support plan.

Post Placement Visits

Formal "inspection visits" are made to see if the support plan is being followed and to determine how well the individual is adjusting to his/her new home. Everyone receives a visit within the first seven days of a move and again within the first thirty days. However, more visits can be made if the person's needs dictate additional visits. Written reports follow each visit.

Family Resource Center

Each month this space will highlight different disability and transition specific print and video resources available to borrow free-of-charge from the Center for Disability Information and Referral (CeDIR), part of Indiana University's Indiana Institute on Disability and Community.

The resources listed here can be obtained by calling CeDIR toll-free at 1-800-437-7924. Borrowers can keep the materials up to four weeks and the material will be mailed directly to your home. The only expense to the borrower is the cost of returning the material via US mail.

This month's featured selections:

- *Indiana's 317 Plan: Profiles of Success* by the Indiana Family and Social Services Administration (Video - 2000)
- *Journeys in Progress: Stories From the Community* by Indiana University's Indiana Institute on Disability and Community (Video - 1996)
- *I belong out there: Finding Fun and Friendship in the Community* by Irene Ward and Associates. (Video - 1995)

For more information in CeDir, visit their web site at: www.iidc.indiana.edu/~cedir

Deinstitutionalization In America

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will support their loved one in their new home.

Are these results just from a few places?

These results of greater quality of life in the community vs. developmental centers or institutions, come from many studies including those from such states as: Arkansas, California, Colorado, Louisiana, Massachusetts, Minnesota, New Hampshire, New York, North Carolina, Oklahoma, Oregon, Texas, and West Virginia and other states. More than 20 state institutions for people with developmental disabilities have closed since 1995. At least 5 states no longer have state institutions for people with developmental disabilities. At least four other states have fewer than 300 people with mental disabilities in state institutions.

These trends are not simply fads. While moving is difficult, all of the evidence from every study shows that the vast majority of people are better off in the community and have a much improved quality of life.

What about how families feel when state institutions are closed?

The closing of institutions in states is a time of concern for people with disabilities and their families. This is one reason why it is important to plan very carefully for each person's move to the community. More than 20 studies of families tell us these things: before deinstitutionalization, most families

were reasonably satisfied with the situation for their loved one; most did not want their loved one to leave the institution. However, within one to two years, the vast majority of family members changed their attitude about community living for their loved one and were happy about it. The vast majority of families have noted and been pleased about the improvements in quality of life for their loved one.

It is important that family members and people with disabilities know that their concerns matter when institutions are closed. While the situation is of concern, it is an important time to tell Indiana government, case managers and community programs what is important. People leaving Muscatatuck, and their families, have the right tell everyone what is important for a happy life: where to live, who to live with, what supports are needed and how the person likes to spend their time.

Family and Employee News Are Available On-Line

Both the *Family News* and *Employee News* newsletters are posted on-line each month. FSSA's Muscatatuck/Madison Transition Process web site has added the newsletters as a feature. The web page can be viewed at:

www.IN.gov/fssa/transition

Contact Us!

FSSA maintains a web site, a toll-free phone number, and this newsletter to help keep MSDC and MSH families fully informed.

Anyone who would like to receive this newsletter can call the number listed and leave their name and address. They will then be added to our mailing list.

The web site features questions discussed at family and employee meetings, the final report from the Governor's Council on State Operated Care Facilities, updates on the *Olmstead* process, articles, and more.

You can visit the web site at:
www.IN.gov/fssa/transition

If you have any questions, comments or concerns, or if you would like to request copies of items on the web site, write to:

Secretary, FSSA
402 W. Washington St.,
Room W461
Indianapolis, IN
46207-7088
Attn: MSDC/MSH

or email:

OfficeOfTheSecretary@fssa.state.in.us

or call toll-free, 24 hours a day:

1-800-903-9822

You can also call this number to express any concerns you have about the services that your loved one receives after leaving MSDC or MSH.